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NEW EXAMPLES AND APPROACHES IN METHODOLOGY FOR THE WRITING OF THE HISTORY OF DISABILITY

1. INTRODUCTION – THE CONTEXTUAL FRAMEWORK

1.1. *Discard or hold in high esteem?*

A specific vantage point in research efforts in the context of the history of disability

In this paper our scrutiny regarding the history of disability aims to undertake the reconstruction of *patterns perceived in the context of both the acceptance and exclusion of persons with disability*. The continuous revisiting of this topic, broken down to research-related questions formulated time and time again, is an essential ingredient of the research effort, due partly to the changing components perceived in the development of society, partly to new findings rooted in the nature of science in development. The primary focus of our paper is related to specific methodological issues in the context of the history of disability.

1.1.1. A social issue to provide the background to our research effort

The social issue which necessitates the invocation of the history of disability as a vantage point to be provided – a background, as it were, to the whole concept of research – is *the oppression of persons with disability* in constantly changing forms at various epochs throughout the history of social as well as cultural development. This spectacularly visible phenomenon justifies the need for scrutiny while providing a context for the everyday relevance of that issue.

1.1.2. Our research-related question

The focus, in a nutshell, of our interest is this: *does social development point to the strengthening of the trend reflected in the acceptance of people with disabilities* (as is suggested by Kálmán–Könczei 2002) *or does the opposite seem to be the case?* Is the term 'social development' relevant at all in this context? Or would social advancement, perhaps, be a more relevant notion to use (Bloch 1965)? Or could it be the case that neither term might be considered valid? At the same time, our research-related question is not pertinent from the perspective of social philosophy; it

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is empirically determined by facts which, in the course of everyday events, both affect the lives of and inflict suffering on people with disabilities.

1.1.3. Our hypothesis formulated during our historical research

Our hypothesis based on previous works related to the history of disability (Könczei 1987; Kálmán–Könczei 2002; Könczei 2014) as well as relevant literature (e.g. Stiker 2007; Rose 2006; Adelson 2006; Dasen 1993; Braddock–Parish 2001; Longmore–Umanski 2001; Foucault 1988 and 1990; DHE 2007 etc.) is that *there is no such thing as linear 'development', one that is seen pointing towards an increasingly positive outcome*. Nor does the notion of 'spiral' exist in the history of disability. There have been various historical movements determining the lives of those affected by them. These movements have diverse, constantly changing patterns of *acceptance and exclusion*. Depending on specific historical periods, the patterns are different in form, providing a mixture, to a varying degree, of several so-called new models (see later in this chapter).

1.1.4. The methods of scrutiny and the notions thereof

Whether or not our research is capable of producing results is, on the one hand, contingent on the *strength of the method opted for*, and, on the other hand, on the degree to which those results are perceived to be in synch with actual facts. In what follows, a broad array of sophisticated methodological tools will be presented with the aim of penetrating both the scope and depth of the enormity of problems to be addressed.

1.) Our understanding of the history of disability allows for an interpretation according to which it is a descriptive and analytic discipline, admittedly free neither of social criticism nor its own set of values – a discipline cutting across various other fields of science.

2.) The fundamental principle applied in our scrutiny is the premise that the history of disability is the history of people with disabilities, particularly because 'man' is a term applicable only to a person with a history. That history *exists*. And because it does exist, the 'only' task to undertake through research is to reconstruct it. (Reconstruction can be achieved through diverse approaches. One such approach is to be presented in this paper). With all its initial results, our reconstruction effort laid out in this chapter does not claim to be more than a *fragmented* sort of achievement.

3.) If reconstruction is undertaken by looking back on the lives of people who lived sometime in the past, a historical view of this sort cannot be conveyed without including human figures, faces or destinies. By applying this *face-centred* (i.e. story-centred) method, we follow in the footsteps of Lyotard (1984) who replaced the traditional notion of history and the well-known, chronological etc. interpretation of history with *stories* by harnessing the findings of hermeneutics and post-structuralism. If, for example, we know that those who are oppressed are voiceless – as was explained by Gayatri Spivak: Chakravorty 2006 – the reconstruction of their voices will be undertaken from their lives and destinies (see, for example, Hottentot Venus later in this chapter).

4.) Stories about individuals or 'faces' are written, whenever possible, by following Hermann Gunkel's principle of setting in life (*Sitz im Leben*).

5.) By following Marc Bloch's teaching, 'throughout our research, in the dusty atmosphere of archives and the silence of museums, it has always been the person who once lived that we keep looking for'.

6.) While conducting our historical examination, the compartmentalization of our findings for the purpose of meeting the needs of all-inclusive development patterns should be avoided (Kámán–Könczei 2002).

Throughout the OTKA research, the 6-point methodological summary above has been the guiding principle for the historical aspects of that research.

Top of the list among *fundamental items of terminology* is the notion of *disablism*. It is an all-inclusive term to cover phenomena such as exclusion, expulsion, disability-based discrimination, negligence, abjection etc. It refers to the innocence of the person affected, while underscoring the *role of the social setting*.

The second fundamental terminological item is *models*. The most important models of disability are: the moral model, the medical model, the human rights model and the social model. Based on Könczei–Hernádi (2012), we understand them to be cognitive, thought-generated constructions which, in the course of history, are guidelines for thinking and acting in the context of our subject – disability and people with disability.

There is a third, albeit not very often identifiable fundamental terminological item among the initial research findings: *Weltanschauung*, ‘world view’, a word of German origin. In our case it provides a backdrop for historical observation. Certain phenomena with particular characteristics, partial processes and faces will, at some point in the future – not during our current research, though –, become part of the existing timeline elements.

2. ‘SMALL PEOPLE’ – AND MODELS

2.1. *The dwarf syndrome*

2.1.1. Changes in the role of the dwarf

Dwarfish people (the valid term used today is *people with a short stature*, sometimes referred to as *pygmoid people*) are probably the most *abused, most exploited* human figures in social history. The roots of stereotypes perpetuated in connection with these people are so deep and so easy to reproduce that they have, over long periods of history, continued to exist in a largely unchanged form. As has been the case many a time – cloaked in a variety of roles and changing attitudes – what we have *here* is the body of a human being; the interactions between a peculiar human body and the functioning of society.

Here is a list of the typical roles of pygmoid people in history:

- circus act*, entertainer, clown (a role often assigned to them during various periods in history);
- object* (e.g. a valuable property, an object of sexual gratification, a sports instrument in an attraction called *midget tossing*, which continues to be in existence even in the 21st century – see further details of this later);
- miner – due to small body size;
- smith, craftsman – particularly in northern mythology;
- evil demon or its opposite: exorcist (also in the form of an amulet);
- servant, slave;
- mythical figure;
- hero of a tale (e.g. Tom Thumb or the Seven Dwarves);
- character depicted in works of fine arts, e.g. in paintings by Van Dyck, Velázquez, Toulouse-Lautrec, Pablo Picasso;

or characters depicted in various literary works (by Jonathan Swift, Walter Scott, Edgar A. Poe, Charles Dickens, Par Fabian Lagerkvist, Hermann Hesse, Günther Grass, J. R. R. Tolkien and others); and occasionally featuring in films as a hero or character: The Wonderful Wizard of Oz, Snow White and the Seven Dwarves, The Hobbit, Twin Peaks, Freaks, The Station Agent, The Tin Drum, Smurfs etc.

2.1.2. Discrimination against people with a short stature and the imprinting of its effect in the course of history

Ancient Egypt

For people like Seneb the dwarf, (for further details, see Kálmán–Könczei 2002, pp. 35–37), the prestige is derived from the dwarf gods of the era as several of their gods (such as Ptah-Pataikos or Ptah-Sokar) are the depictions of the Creator God Ptah from different epochs. The power and force of God is symbolized through depicting him sometimes either with a scarabeus on the head or standing on two crocodile heads (Dasen 1993).

God Bes, the dwarf god and household deity that protected mothers, women in labour and birth, produces the same effect. This makes it easier to understand why Seneb, despite – or maybe *because of* – his diminutive human body, held twenty various titles (Dasen 1993, p. 127). As a court employee he held various offices. Moreover, he had clerical functions as well.

In a publication, archeologist Zahi Hawass, finder of the statue of the dwarf Perniankhu, the *royal entertainer*, proposed a theory in connection with Seneb. The statue dates back to the Fourth Dynasty of Ancient Egypt (2575–2467 BC). He was described as being ‘the king’s dwarf, Perniankhu of the Great Palace, who was prepared to entertain his Master every day’ (Hawass 2010, p. 26). The assumption established on the basis of research findings in connection with the chronological proximity and the nearness of funeral sites is that Perniankhu might have been Seneb’s father (Hawass 2010, p. 88).

Another source from Ancient Egypt is the Instructions of Amenemope, son of Kanaht, from around 1100 BCE. Chapter 24 (01.03) reads:

‘01 Do not laugh at the blind man
02 Do not tease the dwarf
03 Do not cause hardship to the lame’.

In the ancient Jewish society

the following was part of the duties of priests: ‘No man [...] who has any defect, may approach to offer the bread of his God [...] a blind man or lame, who has marred face or any limb too long, a man who has broken foot or broken hand, or is a hunchback or a dwarf [...]’ (Leviticus, 21., 17–20).

What people with disabilities were denied in that culture and period was probably the most important social function. If the current volume is to view these phenomena from the vantage point of disability studies rather than cultural anthropology, it will be difficult to find arguments to prove that a ban of this kind is non-discriminative. What is known today as *ablism* – the dictatorship of ablism (see for more details in the following chapter) – was, apparently, the driving force behind this sort of

prohibitory attitude. However, a very serious consequence, its *effects on history*, can be attributed to the ban itself as there is no reason to assume that if a book is used for several thousand years by successive cultures and civilizations (the European, so-called Judeo-Christian culture), one of its fundamental contentions will have no consequences at all.

That would be a wrong assumption, because *the effects on history* are to be seriously reckoned with – they constitute a perilous *paradigm* which *inculcates into our perception of history* and into various segments of successive European cultures and the entire European civilization the idea, formulated in different languages, that *this not only can but must be done*. Here we need to anticipate one of the key findings of the historical aspects pertaining to our research: *The dominant discourse in a particular era does not come into being without antecedents. That being the case, the discourse itself can only be shaped with immense difficulty, given the fact that it is rooted in the effects imprinted and even engraved on top of one another by earlier historical periods.*

The institutional aspects of the freak show

The ‘engravings’ from various historical periods became even deeper during the first half of the 20th century – the period of *freak shows and picture postcards* – inflicting further damage on what has been turned by this post-modern age into a largely predestined future for dwarves. A woman with a diminutive body, somewhat vestigial hands and oddly shaped legs, not only became an *item on display* in a show during the World Exposition between 1939 and 1940 in New York City, she was also ‘commercialized’, her photograph having been sold as a picture postcard. The phrase used in the caption included the word ‘sweet’. She was described as ‘Mignon, the penguin girl’. A thought-provoking circumstance is the fact that she had by then reached 30 years of age, i.e. she was no longer a girl. Another interesting fact is that *no name was used* in referring to her. In addition to what Gayatri Spivak’s works have taught us – see an earlier part of this chapter – i.e. that the oppressed are voiceless, here is a new conclusion to be drawn from the history of disability: very often they do not even have a name; there have been examples, particularly in some institutions, of names being replaced by *numbers*. These people are often called by that number, not their real name. Even their graves have that same number on them. As a footnote, the name of the woman in the above example was Ruth Davis. She was born in 1910 and is known to have been married twice. She had a son and is said to have died in 1960.

At that time, thousands of people lived a life similar to that of Ruth Davis, having to feature in freak shows and be shown on picture postcards. In addition, this period ended with the emergence of fascism and the outbreak of World War II, which *deepened those historical engravings* even further: in the 1940s Mengele, the infamous physician, one of the death factory masterminds and an aficionado of experiments, went into extreme lengths in performing both his experiments and his research by selecting the ‘dwarves’ from all over the Nazi empire (Koren–Negev 2005). Other historical imprintings, which had an effect on science, should also be noted. Other examples from these have also been drawn in this chapter. As a result of the ‘protection’ of the human material selected for Mengele’s experiments, seven dwarfish people of Hungarian nationality – the entire Ovitz family – survived, which can be put down to mere luck. Another twist in the story is that one of the survivors, Perla Ovitz, bemoaned the death of Mengele. (The story is recounted by Barbara Duncan in the German language documentary entitled *Liebe Perla*).

The only reason making it possible for medical experiments to be performed on dwarfish people, while barring such experiments from being conducted on *humans*, was the assumption that pygmoid people were not humans. The fascist mindset was similar in eliminating persons with an intellectual disability and those with a psychosocial disability – a psychiatric type of disorder – in the course of *Aktion T4* (see more details on this later in the chapter on adoption).

3. WOMEN BECOME SINFUL HUMAN BEINGS – AN ACCUSATION THEY CANNOT RID THEMSELVES OF: CARDINAL POINTS IN THE ANCIENT AND MEDIEVAL NARRATIVES OF ADOPTION

3.1. *Abandoning newborns*

The Second Book of Moses – Exodus 2:3 – describes events that are fundamental in the Judeo-Christian narrative: the infant Moses is laid out in a papyrus basket by his mother. In this case the *imprinting of historical effects* mentioned earlier on is a phenomenon anticipating a course of action – with or without a basket – for people living in future societies as a *possible* and *valid* option to follow.

Based on ancient Greek traditions, historical imprinting carries with it the conviction that children with serious disability are *not to be considered human beings* (see later in this chapter). In this chapter the *effects of imprinting dating back to the Middle Ages* should also be noted. Those effects will invariably become part of the dominant discourse in future historical periods.

Thus in the ancient world of Greece the symbolic role of an institution was assigned to Taygetus. The following excerpt is by Plutarch, the famous biographer:

‘Offspring was not reared at the will of the father... if it was ill-born and deformed, they sent it to the so-called Apothetae, a chasm-like place at the foot of Mount Taygetus in the conviction that the life of that which nature had not well equipped at the very beginning for health and strength, was of no advantage either to itself or the state’ (*The life of Lycurgus* 16, 1–3).

Plato’s attitude also falls in line with the above approach: ‘those [...] who are born defective, they will properly dispose of in secret, so that no one will know what has become of them’ (*Republic* 460c). Aristotle, the scholar, equally favours the practice of disposal: ‘no deformed child shall be reared [...]’ (*Politics* 1335b).

The relevant practice in Ancient Greece is summarised below in the following manner, based on Kálmán-Könczei (2002, pp. 40–42): *Before tossing a newborn off a cliff or exposing it*, the infant was presented to the father, who could decide to consider it unwanted. The custom of infants having to be examined by leading elder Spartans from the child’s tribe was a practice observed mainly in Sparta. The custom of newborns being *tossed off cliffs or being otherwise exposed* was maintained despite the fact that the burying of the dead was an important ritual in the culture of Ancient Greece. (see, for example, *Antigone* by Sophocles). It should be borne in mind that being unburied is the harshest punishment of all; the souls of the unburied dead will never rest, therefore they will keep roving to the end of time. It is clear, therefore, that Ancient Greece was a civilization which considered newborn infants with a disability inhuman.

Ancient Greek culture, with all its outstanding, rich legacy that includes Acropolis, the Colossus of Rhodes, its brilliant philosophical questions, the institution of democracy

and the Septuagint, also left its mark through the effect it had on successive periods in history in the course of social development via the phenomena mentioned above.

3.2. *Infants exposed and replaced, the witch's bastard i.e. the infernal origin*

The Middle Ages, while being shrouded in mythology, was a period of cool and realistic ambience, also functioning as the myth of origin that perpetuated the subject of the infant born with a serious physical – occasionally mental – impediment. This phenomenon has been recorded in the German language via the term *untergeschobene Kinder*, while in English the term *changelings* has been used. A corresponding term has also been used in the world of Hungarian fairy tales (see more details, e.g. Kálmán–Könczei 2002).

The insinuating question, naturally, is 'how could, by any chance, two mentally healthy parents with perfect bodies have a child like that?!' Either the woman slept with the devil (i.e. the child was, according to the moral model, conceived in sin), or if evil, diabolical forces – witches or the devil himself – replaced the healthy baby with some witch's repulsive offspring.

What is the message conveyed by the myths of origin, rooted in our European mythologies, regarding the beginnings of disability? The message is that the woman slept with the devil, that the *proneity to sin* of the 'unruly, uncontrollable female body' is to blame for this undesirable outcome, and that serious disability is not human, therefore its product cannot be human, either.

6. SUMMARY

The Achilles' heel of the historical approach described in this chapter is, undoubtedly, its methodology. As the objective of the current historical review is to have a clearer view as well as an overview of all unknown historical periods, to approach the current methodology with a *critical mind* and to provide it with an additional *supplement* is of crucial importance. (An example for achieving the latter aim could be a chronological, pictorial summary – if this can create a clearer view – even if it cannot be published for technical reasons.) Most former methods thus clarified, along with those to be introduced as new ones, are to be considered new when compared with studies so far completed on the history of disability. During the 1990s and the early 2000s the first attempts to show human *faces*, i.e. the fates of individuals were made. Now the first additional steps have been taken by reconstructing some new faces such as *Saartjie Sawtche* (Sarah Baartman) the French boy from Lacourt, Randolph Silliman Bourne, Virginia Woolf. A greater depth of elaboration regarding the story will become possible in the future, when all the research findings will be included in one, more comprehensive work, in which previous errors will be rectified. This approach will offer a new methodological alternative, now at the embryonic stage: the juxtaposition of female faces – which have become faces with disability, due to the workings of society – with male faces, i.e. a more intense combination of feminism as part of the history of disability with the notion of gender, used as a complementary methodology.

A note on the question 'development or progress?', asked by the philosopher Ernst Bloch in 1965: findings so far have not really added a lot to that question. What we do know now is that the history of disability is not a *story of salvation*, in which history, having encountered minor hitches along the road, is seen progressing towards the

glorification of people with disability and equal opportunity of a kind that is more complete now than previously. Based on the initial research findings, there is a strong likelihood that neither formula describing either the road *from Taygetus to that of equal opportunity*, or *from equal opportunity to Taygetus*, can adequately describe fundamental operational alternatives or basic stages in development. (Findings in other specific fields of research might, however, point to a different conclusion). It appears to be the case, though, that disability studies, together with the social model and the human rights model, seem to be strong enough safeguards to reduce the possibility of the future emergence of oppressive tendencies, unlike the hundred years from the recent past.

One of the findings of the current research is the introduction of the dwarf syndrome as a first step. The historical perspective is accompanied by other elements which are of relevance today, such as *dwarf-tossing* or *catch a dwarf*. Their significance lies in the fact that they underscore, yet again, the significance of *historical imprinting* and *historical engravings* – the subject of this chapter – as well as the *effect that they have on the dominant discourse*. In the 21st century, dwarf tossing is an occasional sports event held in some Anglo-Saxon countries. Strong men grab dwarfism-affected persons wearing protective helmets by the waist and by another spot on their bodies, then throw them parallel to the ground – like an object or a javelin or a shot put by a shot putter. With the crowd cheering, the winner is whoever has the longest throw. Bets are also allowed.

Catch a dwarf is an event with German origins. Rather than tossing dwarfism-affected persons, this event is held at parties where participants are invited to chase them (the event is known as *Liliputaner Action* in Germany). At one such party in 2013, the first prize to go to the winner was a plasma TV. The winner had to catch and lock up the ‘dwarf’. A dwarfism-affected person was injured during the event, which caused a scandal.

Historical imprinting and *its effect on the dominant discourse* is to be interpreted in the context of CRPD as these two phenomena offer an answer to the question how it is possible to organize ‘dwarf-tossing’ and ‘catch a dwarf’ in states that have ratified the Charter of the United Nations. *Old elements of the dominant discourse, which have been present for hundreds of years or – in our case – thousands of years, appear to be stronger than new ones.*

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